

On the number of intersex people

By [Admin](https://oii.org.au/author/admin/) on 28 September 2013

There are no firm population figures for people with intersex variations. The reasons for this lie in the lack of accurate recording of data on intersex diagnoses, and ideology.

We have seen estimates range from 1 in 1,500 or 2,000 births to 4%, and we recommend a figure of 1.7%, despite its flaws. This was published by Blackless and others in the American Journal of Human Biology, a peer reviewed scientific journal, and also by Anne Fausto-Sterling, Professor of Biology and Gender Studies at Brown University in the US. No more accurate sources of data yet exist.

Upper bound estimates

The higher figure of 4% has been attributed to University of Queensland [Professor Peter Koopman](http://www.uq.edu.au/uqresearchers/researcher/koopmanpa.html) (<http://www.uq.edu.au/uqresearchers/researcher/koopmanpa.html>). However, he has advised us that he cannot verify such a figure.

The 4% figure was apparently first quoted by [Dr John Money](http://en.wikipedia.org/wiki/John_Money) (http://en.wikipedia.org/wiki/John_Money) and was attributed to Professor Koopman in error by [Cosmo Magazine](http://www.cosmosmagazine.com/node/1461) (<http://www.cosmosmagazine.com/node/1461>). Money was regarded as a preeminent authority on intersex issues until [revelations](http://www.amazon.com/As-Nature-Made-Him-Raised/dp/0061120561/) (<http://www.amazon.com/As-Nature-Made-Him-Raised/dp/0061120561/>) regarding the David Reimer case (this classic medical case study concerned the gender identity of a boy raised as a girl after a botched circumcision).

Anne Fausto-Sterling quotes Money's estimate in her [paper, *The Five Sexes*](http://capone.mtsu.edu/phollowa/5sexes.html) (<http://capone.mtsu.edu/phollowa/5sexes.html>).

Lower bound estimates

Many sources cite lower bound estimates of 1 in 1,500 or 1 in 2,000 live births. These tend to exclude many intersex variations that are otherwise considered by medicine now to be "Disorders of Sex Development" or "DSD"; they focus on a narrower range of traits where external genitalia are "ambiguous". For example, Professor Alice Dreger has [said](http://www.isna.org/articles/ambivalent_medicine) (http://www.isna.org/articles/ambivalent_medicine), in 1998:

“ One 1993 gynecology text estimates that “in approximately 1 in 500 births, the sex is doubtful because of the external genitalia.” I am persuaded by more recent, well-documented literature that estimates the number to be roughly 1 in 1,500 live births.

The frequency estimate goes up dramatically, however, if we include all children born with what some physicians consider cosmetically “unacceptable” genitalia.

This approach is also seen in a 2002 paper by Dr Leonard Sax [which states](http://www.ncbi.nlm.nih.gov/pubmed/12476264) (<http://www.ncbi.nlm.nih.gov/pubmed/12476264>):

“ Anne Fausto-Sterling’s suggestion that the prevalence of intersex might be as high as 1.7% has attracted wide attention in both the scholarly press and the popular media. Many reviewers are not aware that this figure includes conditions which most clinicians do not recognize as intersex, such as Klinefelter syndrome [47,XXY], Turner syndrome [45,X], and late-onset adrenal hyperplasia. If the term intersex is to retain any meaning, the term should be restricted to those conditions in which chromosomal sex is inconsistent with phenotypic sex, or in which the phenotype is not classifiable as either male or female. Applying this more precise definition, the true prevalence of intersex is seen to be about 0.018%, almost 100 times lower than Fausto-Sterling’s estimate of 1.7%.

In this context, a [2006 shift in medical terminology](http://pediatrics.aappublications.org/content/118/2/e488) (<http://pediatrics.aappublications.org/content/118/2/e488>) is illuminating. “DSD” was defined by clinicians as a “replacement” medical term for intersex. The term itself remains highly contested: Australian and many other intersex organisations regard it as inherently pathologising; it tends to sanction medical intervention. Our contention was [supported by the Australian Senate’s Community Affairs Committee in a 2013 report](https://oii.org.au/24058/statement-senate-report-involuntary-or-coerced-sterilisation-intersex-people/) (<https://oii.org.au/24058/statement-senate-report-involuntary-or-coerced-sterilisation-intersex-people/>) on the “Involuntary or coerced sterilisation of intersex people in Australia”.

Even though we object to the term “DSD”, it encapsulates a range of atypical physical or anatomical sex characteristics. These share in common their non-conformance with medical and social sex and gender norms. This non-conformance with stereotypical standards for male and female is why intersex differences are medicalised in the first place and, while that remains the case, it makes sense to us to include them in a definition of intersex.

The difference between narrow and broad definitions in medicine is somewhat ideological. The exclusion of some diagnoses that embody atypical sex characteristics but not others seems, at least to us, to be irrational. Intersex people do not share the same identities, but we share common ground in the stigmatisation of our atypical sex characteristics.

Many different, broader – and compatible – definitions now exist in Australian law, regulations and frameworks. The Victorian health department’s 2013 decision-making framework [guidelines](http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions) (<http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>) refer to the term ‘intersex conditions’ as “any set of physical or biological conditions that mean a person cannot be said to be exclusively male or female.”

The Attorney General’s Department has adopted the following [definition](http://www.ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx) (<http://www.ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx>), underpinning gender recognition guidelines published in 2013:

“ An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. Environmental influences such as endocrine disruptors can also play a role in some intersex differences. People who are intersex may identify their gender as male, female or X.

The low figure of 1 in 1,500 or 1 in 2,000 live births is not borne out by data published elsewhere. The NSW Ministry of Health reports data from the [New South Wales Mothers and Babies Report 2009](http://www0.health.nsw.gov.au/pubs/2011/mothers_babies_2009.html) (http://www0.health.nsw.gov.au/pubs/2011/mothers_babies_2009.html) showing that infants with visible reportable differences of sex anatomy between 2003-2009 comprised 0.59% of all births, or 1 in 169. No breakdown of additional (often not yet apparent) relevant chromosomal “anomalies” is given. We acknowledge that not all 0.59% of births may be intersex, but it must be remembered, too, that clinical treatment protocols are still predicated on the removal of doubt and assignment of a “true” binary sex in every case. Not one live birth is actually classified as intersex in any register.

Mid range figure: around 1.7%

OII Australia recommends the research quoted by [Professor Anne Fausto-Sterling](http://en.wikipedia.org/wiki/Anne_Fausto-Sterling) (http://en.wikipedia.org/wiki/Anne_Fausto-Sterling) showing intersex to be around 1.7% of all live births. Importantly, by including 45,X and 47,XXY in her statistics published in 2000, Anne Fausto-Sterling has insightfully anticipated the inclusion of those diagnoses under the later, 2006, “DSD” umbrella. In *Sexing the Body*, she includes the following summary:

Frequencies of Various Causes of Nondimorphic Sexual Development

Cause	Estimated frequency per 100 live births
Non-XX or non-XY (except Turner's or Klinefelter's)	0.0639
Turner Syndrome (<i>45,X or 45,XO</i>)	0.0369
Klinefelter Syndrome (<i>47,XXY</i>)	0.0922
Androgen Insensitivity Syndrome (<i>i.e. Complete AIS</i>)	0.0076
Partial Androgen Insensitivity Syndrome (<i>PAIS</i>)	0.00076
Classic CAH (omitting very high frequency population) (<i>Congenital Adrenal Hyperplasia</i>)	0.00779
Late-onset CAH	1.5
Vaginal agenesis	0.0169
True hermaphrodites (<i>now termed 'Ovotestis'</i>)	0.0012
Idiopathic	0.0009
Total	1.728

Source: Anne Fausto-Sterling, 2000, *Sexing the Body*, Basic Books, page 53. ISBN 978-0465077144
Our notes on terminology are emphasised in *italics*.

The background analysis was published by Blackless *et al* in the *American Journal of Human Biology* ([http://onlinelibrary.wiley.com/doi/10.1002/\(SICI\)1520-6300\(200003/04\)12:2%3C151::AID-AJHB1%3E3.0.CO;2-F/abstract](http://onlinelibrary.wiley.com/doi/10.1002/(SICI)1520-6300(200003/04)12:2%3C151::AID-AJHB1%3E3.0.CO;2-F/abstract)) in 2000, which found that:

“ frequency may be as high as 2% of live births. The frequency of individuals receiving “corrective” genital surgery, however, probably runs between 1 and 2 per 1,000 live births (0.1-0.2%).

Multiple factors affect the accuracy of these statistics, and rates of pregnancy terminations and genetic diversity in different populations mean that the figure is somewhat flawed.

Genetic differences vary in different populations

Because intersex is innate, typically genetic, population figures vary somewhat around the world, and the figure of 1.7% omits populations with high rates of CAH. Fausto-Sterling states:

“ The figure of 1.7 percent is an average from a wide variety of populations; the number is not uniform throughout the world...
The frequency of the gene for CAH varies widely around the world. One study found that 3.5 per thousand Yupik Eskimos born had a double dose of the CAH gene. In contrast, only 0.005/1,000 New Zealanders express the trait...
Among Ashkenazic Jews, the number [of a related gene] rises to 37/1,000.

In an Australian context, higher than average population figures for CAH are also apparent (<http://www.ncbi.nlm.nih.gov/pubmed/23039988>) in some indigenous communities. 5 Alpha-Reductase Deficiency is noted to be relatively more common (<http://www.ncbi.nlm.nih.gov/pubmed/1831738>) amongst some linguistic groups in PNG.

There are many more intersex variations

Not all known intersex traits are included in the table. These include diagnoses like 5 Alpha-Reductase Deficiency and complex (<http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>) Hypospadias.

Fausto-Sterling's figure for idiopathic intersex traits is also important to note. Idiopathic diagnoses are those where the aetiology (cause or history) is not known. In 2013, Professor Olaf Hiort, chief of the Division of Paediatric Endocrinology and Diabetes in the Department of Paediatrics at Lübeck University, Germany, recently cited "at least 40" distinct intersex variations, and presented a rather different – and substantially larger – figure (http://www.gla.ac.uk/media/media_279274_en.pdf):

“DSD comprise a heterogeneous group of differences of sex development with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases.

Ten to 80% is an extraordinary range. It illustrates that neither diagnosis, nor definition (and, we argue elsewhere, nor treatment) are exact sciences.

Anne-Fausto Sterling also suggests that population figures “may be on the rise”, noting a birth via in vitro fertilisation, and concern regarding “environmental pollutants that mimic estrogens”.

Terminations

On the other hand, population figures are likely to have changed over time due to terminations. For example, CAH, 45,X and 47,XXY are testable via amniocentesis, and many identified pregnancies may be terminated including up to 88% in studies of 47,XXY fetuses diagnosed prenatally. (<http://www.dshs.state.tx.us/birthdefects/risk/risk19-kliefelter.shtml>)

Summary

Given that intersex people only come to the attention of data collectors through chance or an apparent medical reason, the actual numbers of people with intersex variations are likely to be as much as 1.7%. Despite the limitations of the data, 1.7% seems more justifiable than alternatives, to date.

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